



2005 ASSEMBLY BILL 1098

March 7, 2006 - Introduced by Representatives TOWNSEND, GUNDERSON, MONTGOMERY, MUSSER and SHERIDAN, cosponsored by Senator ROESSLER. Referred to Committee on Public Health.

1 **AN ACT** *to renumber and amend* 253.12 (1) (b); *to amend* 69.03 (12), 69.20 (2)
2 (a) (intro.), 69.20 (3) (b) 3., 69.20 (3) (c), 69.20 (3) (d), 253.12 (1) (a) (intro.),
3 253.12 (1) (a) 1., 253.12 (2) (a) (intro.), 253.12 (2) (am), 253.12 (2) (b), 253.12 (2)
4 (e), 253.12 (3) (a) 1. (intro.), 253.12 (3) (a) 1. c., 253.12 (3) (c), 253.12 (4) (a),
5 253.12 (5) (a) 1., 253.12 (5) (a) 2. and 253.12 (5) (a) 4.; *to repeal and recreate*
6 253.12 (2) (d); and *to create* 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (1) (f), 253.12
7 (1) (g), 253.12 (2) (a) 3., 253.12 (2) (a) 4., 253.12 (5) (c) and 253.12 (5m) of the
8 statutes; **relating to:** the birth defect prevention and surveillance system.

Analysis by the Legislative Reference Bureau

Under the birth defect prevention and surveillance system (system) in current law, pediatric specialty clinics and physicians are required to report to the Department of Health and Family Services (DHFS) any birth defects of infants or children who are diagnosed or treated in the clinics or by the physicians. A "birth defect" is defined as a structural deformation, disruption, or dysplasia or a genetic, inherited, or biochemical disease that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development. An "infant or child" is defined as a human being from birth to the age of two years. DHFS may not require a pediatric specialty clinic or physician to report the name

ASSEMBLY BILL 1098

of a reported infant or child if the parent or guardian of the infant or child refuses in writing to consent to the release of the name or address of the infant or child.

Also under current law, information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only or that involves the birth of a child to an unmarried mother may be disclosed only in certain instances. One instance is disclosure of this information, under an interstate cooperation agreement, from the vital record of the resident of another state or a resident of this state born in another state, for use by the state registrar in compiling statistics. Another instance is disclosure of statistical or medical information for use in the conduct of official duties of a federal agency, a Wisconsin governmental agency, or the agency of a county, city, town, or village. In addition, hospitals and funeral directors must provide and the state registrar must accept reports of certain fetal deaths. Before destroying these reports, the state registrar may record the reports' information for use in medical research and use the information to compile statistics.

Lastly, under current law, DHFS must establish and maintain an up-to-date registry that documents the diagnosis in this state of any infant or child who has a birth defect. Among the information that DHFS is required to include in the registry is information that will facilitate the development of primary preventive strategies to decrease the occurrence of birth defects without increasing abortions.

This bill changes the process by which the parent or guardian of an infant or child may decide not to consent to the release of the infant's or child's identifying information, to require that a physician or physician's designee first inform the parent or guardian of the intent of the system and to require signature of the parent or guardian on a DHFS form. Further, the bill specifies a process by which, using the DHFS form, the parent or guardian of an infant or child may effect withdrawal of consent to the release of identifying information about the infant or child, and requires that, if consent to the release is withdrawn, DHFS remove the information from the system. DHFS must prescribe and distribute to pediatric specialty clinics and local health departments the form for these purposes by January 1, 2007.

The bill requires the division of DHFS that deals with vital statistics to report to the system information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only, including this type of information that is available under an interstate cooperation agreement, if this disclosure is agreed to by the other state. In addition, the bill requires the entity that contracts with the Department of Administration for collecting, analyzing, and disseminating health care information of hospitals and ambulatory surgery centers to report to the system concerning birth defects as recorded in public use data files of hospitals and ambulatory surgery centers.

The bill authorizes DHFS to contract with an entity to perform the development of primary preventive strategies to decrease the occurrence of birth defects as information to be included in the birth defect registry.

The bill also permits the state registrar to record information from reports of certain fetal deaths for use in research conducted under the system.

ASSEMBLY BILL 1098

Lastly, the bill includes stillborn humans, as defined in the bill, under the requirements of the system, expands the definition of "birth defect" to include structural malformations, and makes other minor changes.

For further information see the *state and local* fiscal estimate, which will be printed as an appendix to this bill.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

1 **SECTION 1.** 69.03 (12) of the statutes is amended to read:

2 69.03 (12) Accept fetal death reports under s. 69.18 (1) (e). The state registrar
3 may record the information on the reports for use in medical research, including
4 research conducted under s. 253.12 (5) (b), and may use the information to compile
5 statistics. After recording the information on a fetal death report, the state registrar
6 shall destroy the report.

7 **SECTION 2.** 69.20 (2) (a) (intro.) of the statutes is amended to read:

8 69.20 (2) (a) (intro.) ~~Except as provided under sub. (3), information~~ Information
9 in the part of a certificate of birth or divorce or annulment or a marriage document
10 that is designated on the form as being collected for statistical or medical and
11 statistical use only and information in the part of a death certificate that is
12 designated on the form as being collected as statistical-use-only information under
13 s. 69.18 (1m) (c) may not be disclosed to any person except the following:

14 **SECTION 3.** 69.20 (2) (a) 3. of the statutes is created to read:

15 69.20 (2) (a) 3. As provided under sub. (3).

16 **SECTION 4.** 69.20 (3) (b) 3. of the statutes is amended to read:

17 69.20 (3) (b) 3. The information is from the vital record of a registrant who is
18 a resident of another state or who was born in another state and is transmitted to
19 the office responsible for keeping the vital statistics in such state under an interstate

ASSEMBLY BILL 1098

1 cooperation agreement which requires that the information be used for statistical
2 and administrative purposes only and which provides for the retention and
3 disposition of such copies. If under such an agreement the state registrar receives
4 information from an office responsible for keeping the vital statistics in another
5 state, the state registrar may not use the information for any purpose except for the
6 compilation of statistics and, if agreed to by the other state, in meeting requirements
7 for reporting under s. 253.12 (2) (a) 3.

8 **SECTION 5.** 69.20 (3) (c) of the statutes is amended to read:

9 69.20 (3) (c) ~~Notwithstanding sub. (2), a~~ A local registrar may disclose
10 information on a birth certificate or issue a copy of the certificate to a local health
11 department, as defined in s. 250.01 (4), for health or demographic research or a public
12 health program if the local health department pays the copying costs and if the birth
13 of the registrant occurred within the boundaries of the political subdivision served
14 by the local health department or the registrant is a resident of the political
15 subdivision. The local health department may not disclose any information from any
16 copy which it receives under this paragraph to any person and shall destroy the copy
17 no later than one year after receipt.

18 **SECTION 6.** 69.20 (3) (d) of the statutes is amended to read:

19 69.20 (3) (d) Subject to par. (f), the state or a local registrar may disclose
20 information from the vital record of a specified registrant, ~~except information under~~
21 ~~sub. (2) (a), to a federal agency, to any agency of the government of this state, or to~~
22 ~~any agency of a county, city, town, or village if the agency requests the information~~
23 ~~for use in the conduct of its official duties, except that the state registrar may disclose~~
24 ~~information under sub. (2) (a) only in order to meet requirements for reporting under~~
25 ~~s. 253.12 (2) (a) 3.~~

ASSEMBLY BILL 1098

1 **SECTION 7.** 253.12 (1) (a) (intro.) of the statutes is amended to read:

2 253.12 (1) (a) (intro.) “Birth defect” means any of the following conditions
3 affecting a stillborn human or an infant or child that occurs prior to or at birth and
4 that requires medical or surgical intervention or interferes with normal growth and
5 development:

6 **SECTION 8.** 253.12 (1) (a) 1. of the statutes is amended to read:

7 253.12 (1) (a) 1. A structural malformation, deformation, disruption, or
8 dysplasia.

9 **SECTION 9.** 253.12 (1) (b) of the statutes is renumbered 253.12 (1) (cm) and
10 amended to read:

11 253.12 (1) (cm) “Pediatric specialty clinic” means a clinic that is located in a
12 hospital or is a freestanding clinic, the primary purpose of which is to provide
13 pediatric specialty diagnostic, counseling and medical management services to
14 persons with birth defects by a physician subspecialist.

15 **SECTION 10.** 253.12 (1) (e) of the statutes is created to read:

16 253.12 (1) (e) “Research” means a systematic study through scientific inquiry
17 for the purpose of expanding a field of knowledge, including environmental or
18 epidemiological research or special studies.

19 **SECTION 11.** 253.12 (1) (f) of the statutes is created to read:

20 253.12 (1) (f) “Stillbirth” means a birth for which a fetal death report is required
21 under s. 69.18 (1) (e) 1.

22 **SECTION 12.** 253.12 (1) (g) of the statutes is created to read:

23 253.12 (1) (g) “Stillborn human” means a human whose birth resulted in
24 stillbirth.

25 **SECTION 13.** 253.12 (2) (a) (intro.) of the statutes is amended to read:

ASSEMBLY BILL 1098

1 253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall
2 report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect
3 in a stillborn human or an infant or child:

4 **SECTION 14.** 253.12 (2) (a) 3. of the statutes is created to read:

5 253.12 (2) (a) 3. The division of the department that deals with vital statistics,
6 with respect to the information received under s. 69.20 (3) (b) 3. or available under
7 s. 69.20 (3) (d).

8 **SECTION 15.** 253.12 (2) (a) 4. of the statutes is created to read:

9 253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect
10 to public use data files under s. 153.46 (1) (b).

11 **SECTION 16.** 253.12 (2) (am) of the statutes is amended to read:

12 253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillborn
13 human or an infant or child or treatment is provided to the infant or child may report
14 the birth defect in the manner prescribed by the department under sub. (3) (a) 3.

15 **SECTION 17.** 253.12 (2) (b) of the statutes is amended to read:

16 253.12 (2) (b) No person specified under par. (a) need report under par. (a) if
17 that person knows that another person specified under par. (a) or (am) has already
18 reported to the department the required information with respect to the same birth
19 defect of the same stillborn human or infant or child.

20 **SECTION 18.** 253.12 (2) (d) of the statutes is repealed and recreated to read:

21 253.12 (2) (d) If the parent or guardian of a stillborn human or an infant or child
22 for whom a report is made under par. (a) decides, after having been informed by a
23 physician or a physician's designee of the intent of the system under this section, not
24 to consent to the release of identifying information concerning the stillborn human
25 or infant or child and signs the form specified in sub. (5) (c), the department may not

ASSEMBLY BILL 1098

1 require a person specified under par. (a) 1., 2., or 3. to report information identifying
2 the stillborn human or infant or child.

3 **SECTION 19.** 253.12 (2) (e) of the statutes is amended to read:

4 253.12 (2) (e) If the address of an infant or child or the place of delivery of a
5 stillborn human for whom a report is made under par. (a) is included in the report,
6 the department shall encode the address to refer to the same geographical location.

7 **SECTION 20.** 253.12 (3) (a) 1. (intro.) of the statutes is amended to read:

8 253.12 (3) (a) 1. (intro.) Establish and maintain an up-to-date registry that
9 documents the diagnosis in this state of any stillborn human or infant or child who
10 has a birth defect, regardless of the residence of the infant or child or place of delivery
11 of the stillborn human. The department shall include in the registry information
12 that will facilitate all of the following:

13 **SECTION 21.** 253.12 (3) (a) 1. c. of the statutes is amended to read:

14 253.12 (3) (a) 1. c. Development of primary preventive strategies to decrease
15 the occurrence of birth defects without increasing abortions. The department may
16 contract with an entity to perform the development required under this subd. 1. c.

17 **SECTION 22.** 253.12 (3) (c) of the statutes is amended to read:

18 253.12 (3) (c) The department shall, not more than 10 years from the date of
19 receipt of a report under sub. (2), delete from any file of the department the name of
20 a stillborn human or an infant or child that is contained in the report.

21 **SECTION 23.** 253.12 (4) (a) of the statutes is amended to read:

22 253.12 (4) (a) Make recommendations to the department regarding the
23 establishment of a registry that documents the diagnosis in the state of a stillborn
24 human or an infant or child who has a birth defect, as required under sub. (3) (a) 1.
25 and regarding the rules that the department is required to promulgate under sub.

ASSEMBLY BILL 1098

1 (3) (a) 2. and 3. on the birth defects to be reported under sub. (2) and on the general
2 content and format of the report under sub. (2) and procedures for submitting the
3 report. The council shall also make recommendations regarding the content of a
4 report that, because of the application of sub. (2) (d), does not contain the name of the
5 subject of the report.

6 **SECTION 24.** 253.12 (5) (a) 1. of the statutes is amended to read:

7 253.12 (5) (a) 1. The parent or guardian of a stillborn human or an infant or
8 child for whom a report is made under sub. (2).

9 **SECTION 25.** 253.12 (5) (a) 2. of the statutes is amended to read:

10 253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an
11 agency under contract with the department to administer the children with special
12 health care needs program, ~~upon receipt of a written request and informed written~~
13 ~~consent from the parent or guardian of the infant or child~~ under the requirements
14 of subs. (2) (d) and (5m). The local health officer may disclose information received
15 under this subdivision only to the extent necessary to render and coordinate services
16 and follow-up care for the infant or child or to conduct a health, demographic or
17 epidemiological investigation. The local health officer shall destroy all information
18 received under this subdivision within one year after receiving it.

19 **SECTION 26.** 253.12 (5) (a) 4. of the statutes is amended to read:

20 253.12 (5) (a) 4. A representative of a federal or state agency upon written
21 request and to the extent that the information is necessary to perform a legally
22 authorized function of that agency, including investigation of causes, mortality,
23 methods of prevention and early intervention, treatment or care of birth defects,
24 associated diseases or disabilities. The information may not include the name or
25 address of an infant or child or the place of delivery of a stillborn human with a

ASSEMBLY BILL 1098

1 condition reported under sub. (2). The department shall notify the parent or
2 guardian of a stillborn human or an infant or child about whom information is
3 released under this subdivision, of the release. The representative of the federal or
4 state agency may disclose information received under this paragraph only as
5 necessary to perform the legally authorized function of that agency for which the
6 information was requested.

7 **SECTION 27.** 253.12 (5) (c) of the statutes is created to read:

8 253.12 (5) (c) By January 1, 2007, the department shall prescribe and
9 distribute to pediatric speciality clinics and local health departments copies of a form
10 to be used by the parent or guardian of a stillborn human or an infant or child for
11 whom a report is made under sub. (2) (a) in indicating any of the following:

12 1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release
13 of identifying information concerning the stillborn human or infant or child.

14 2. The decision under sub. (5m) by the parent or guardian to remove from the
15 system any identifying information entered for the stillborn human or infant or
16 child.

17 **SECTION 28.** 253.12 (5m) of the statutes is created to read:

18 253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian
19 of a stillborn human or an infant or child for whom a report is made under sub. (2)
20 (a) decides to withdraw consent to the release of identifying information concerning
21 the stillborn human or infant or child, the parent or guardian may request from the
22 local health department or the stillborn human's or infant's or child's physician the
23 form specified in sub. (5) (c). If the parent or guardian decides, after having been
24 informed by the stillborn human's or infant's or child's physician or physician's
25 designee of the information contained in the system under this section, and signs the

ASSEMBLY BILL 1098

1 form, the local health department, physician, or physician's designee shall forward
2 the form to the division of the department that deals with public health. On receipt
3 of the signed form, the department shall remove from the system under this section
4 any information identifying the stillborn human or infant or child.

5 (END)